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At the Membranes of Care: Stories in Narrative Medicine

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Abstract

Recognizing clinical medicine as a narrative undertaking fortified by learnable skills in understanding stories has helped doctors and teachers to face otherwise vexing problems in medical practice and education in the areas of professionalism, medical interviewing, reflective practice, patient-centered care, and self-awareness. The emerging practices of narrative medicine give clinicians fresh methods with which to make contact with patients and to come to understand their points of view. This essay provides a brief review of narrative theory regarding the structure of stories, suggesting that clinical texts contain and can reveal information in excess of their plots. Through close reading of the form and content of two clinical texts—an excerpt from a medical chart and a portion of an audio-taped interview with a medical student—and a reflection on a short section of a modernist novel, the author suggests ways to expand conventional medical routines of recognizing the meanings of patients' situations. The contributions of close reading and reflective writing to clinical practice may occur by increasing the capacities to perceive and then to represent the perceived, thereby making available to a writer that which otherwise might remain out of awareness. A clinical case is given to exemplify the consequences in practices of adopting the methods of narrative medicine. A metaphor of the activated cellular membrane is proposed as a figure for the effective clinician/patient contact.

The theories and practices of narrative medicine propose that a disciplined and rigorous understanding of how stories work and what narrative actions reveal about their participants help to comprehend clinical care. Considering clinical work through narrative frameworks clarifies what equipment might help the clinician or trainee to achieve a position of attention, respect, affiliation, trustworthiness, and even empathy.[1–3] Narrative practices donate to clinical encounters tested methods of teaching and learning of skills in the socio-cultural, interpersonal, and interior dimensions of clinical work.[4,5] Simultaneously, these practices grant us methods to capture the narrative evidence available from a clinical encounter that is usually squandered for want of skills to capture it, thereby increasing the accuracy and, so, the potential effectiveness of clinical work.[6] Framing health care as an undertaking requiring narrative competence helps us to formulate answers to long-standing

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questions about how to teach and practice medical interviewing, professionalism, therapeutic relationships, self-awareness, and reflective practice.[7–9]

Stories, Narrative, and Narrating

Storytelling of one form or another is the hallmark of narrative undertakings. Whether writing a novel, attending a Seder at Passover, testifying at a Congressional hearing, or reading a child to sleep, we use stories to reach and influence one another—toward knowledge, pleasure, faith, action, or love. As a foundation of culture, religion, family, and community, storytelling is one avenue through which we become ourselves.[10, 11]

Stories are the avenue toward telling and, therefore, knowing of the self. The act of giving an account of self has taken on more and more urgency of late.[12] Not only memoirs but works of narration of all kinds—fiction, poetry, drama, essays, journalism—include exposures of whatever might be experienced as the self, both of the teller/writer who gives it and of the reader/listener who receives it. Despite fundamental differences among these genres at the levels of context, form, audience, intention, basis in fact, and medium, these types of narratives share the narrating situation in which the teller/writer offers an account to a listener/reader. Narrative acts sharpen the teller/writer's perception and mobilize his or her imagination, resulting in a singular expressed version of whatever event or state of affairs the narrating represents. If the account succeeds in reaching the listener/reader (which it doesn't always do), these acts influence each listener or reader uniquely.[13,14] Narratives trigger changes of many kinds in both the teller and the listener, yielding meanings that are reciprocally produced by each teller–listener dyad.[15] These conditions obtain in the clinical setting as well as in others.

We see, in the culture at large, great appetite for telling of the self, and we see the results for individuals and groups of having serious opportunities to do so. Some of the telling of self seems trivial or peculiar—reality shows, talk shows, Twitter. But much of the telling of self is critical, formative, and transformative. Psychoanalytic treatment stands as the most intensive model for sustained and reciprocal telling and interpreting of life narratives, both conscious and unconscious, but it is by no means the only form of serious self-telling.[16] Students from kindergarten to medical school are instructed to keep learning journals or portfolios, and many forms of group therapy and trauma treatment rely on the therapeutic potential of telling of life events[17,18] In telling, the teller is able not just to remember but to experience ordeals and their consequences for the self.[19]

In both the arts and the sciences, rigorous attention is increasingly paid to the singular story. Qualitative research, including oral history, anthropological study, participant-observer studies, focus groups, and ethnographic interviews, is founded on the realization that an individual account by a singular person cannot be summarized or collated with data from others, that each particular person has his or her own story that has to be respected and recognized and hailed as significant.[20] The powerful research methods of qualitative scientists allow us to transcend anecdote and its risks and to capture and learn from the evidence of the singular.[21]

Narratives of Clinical Practice

These thoughts are critical to clinical practice, since the care of the sick unfolds in stories. From the beginning of symptoms to the completion of treatment, illness has to be told—first, through symptoms, by the body of the patient to the patient himself or herself, then to family or friends, and then to professionals, who repeat it among themselves. Each illness or episode of care generates multiple accounts: concerns spoken by the patient, reports written by the listening clinician, comments given by other providers, and subsequent responses by

all participants to these reports. Each of these accounts represents a singular point of view and purpose. Despite their great textual variation, together they represent a multi-voiced narrative of illness that is fundamental to and determining of its care. Amid this proliferation of accounts, the central, activating, and organizing event in clinical care occurs when the sick person gives an account of himself or herself, and someone trained to help receives that account.

Clinicians learn of their patients' situations in many ways, including but not restricted to written or spoken accounts of illness. As sensitive registers of patients' moods, silences, and bodily changes, clinicians wordlessly absorb knowledge of their patients, both through the perspective shifts of empathy[22,23] and through the mood shifts of transference and countertransference.[24,25] Although I focus this essay's discussion on the aspects of clinical narratives expressed through language, I do not thereby imply that wordless emissions are not also part of the story.

When we clinicians write the clinical history as absorbed from the patient, our words express something we did not know before we let our words express it. As we register and then represent what we receive from the patient, we clerk the records, depicting, portraying, composing the events of illness that befall others. Whether written in hospital charts, medical journals, diaries, or published novels, telling or writing of clinical experiences confers a comprehensibility on them that is otherwise unattainable.[26]

Psychoanalyst Hans Loewald explains that writing is a sensorimotor act by which one transforms immaterial thoughts into materiality, thereby allowing the writer to communicate that which cannot be apprehended by the senses to self and to others.[27] When we write, we are not simply reporting. We are creating. By virtue of conferring form on erstwhile formless experience, we make it visible, exposing our own experience to ourselves for the first time, bringing into awareness and hence utility that which we may know but that, until the act of composition, resides outside of awareness. Although we do not perceive without representing, even if only in the occipital or auditory cortex, when we write our perceptions, we become our own homuncular amanuensis, committing to language the evidence of experience.

The form conferred on the experience or perception or sensation is as filled with meaning as is the content. The following transcription was made from a hospital chart entry written at St. Luke's Hospital in New York, NY.[28] This is the report of a hospital admission from August 31, 1884, entitled “Cancer of Lung, Haemoptysis”:

> T.J.M., 24 New York Single Conductor
>
> Past History: Father died of pneumonia, mother poisoned by mistake. Has had scarlet fever, intermittent. Denies syphilis. Drinks very little. Has had numerous hemorrhages, the first one seven years ago and the last two years ago, varying from a cup to a quart. Had night sweats.
>
> Present Sickness: At 8:15 last night, while on his car, had a coughing spell immediately followed by a sweet taste in his mouth and bled from his mouth some 20 minutes. Took gallic acid which had good effect.
>
> On Admission: Patient walked in bleeding profusely from the mouth. Pulse strong, at first rapid, later slowed down. Ord. Ergot, tannic acid solution.
>
> Sept 1: Feels better this AM. Ord. Ergot
>
> Sept 3: Very weak and short of breath, still spits blood clots.

> Sept 4: Very much weaker. Infusion Digitalis. Growing cyanotic, still raising blood.
>
> Sept 5: Patient gradually sank at 8 am. No radial pulse. Temperature 105 and at 9:15, quietly died.

The form of this text is familiar to the contemporary medical reader—Past Medical History, History of Present Illness, Social History, and then “continuation sheets” in more or less the order in which we write them today. By virtue of the form alone, the reading confers onto the physician-reader today a sense of proximity to this clinical encounter, of collegiality with this doctor writing over a century ago.

At the same time that we might feel a kinship with this doctor, we also might feel the dramatic differences between us. This young man who died of pulmonary hemorrhage may have had cancer of the lung, as the writer proposed. Despite the patient's night sweats and temperature of 105°, the case was not labeled “phthisis” as were other similar cases written in 1884, the year in which Koch postulated the microbial causation of tuberculosis and other infectious diseases. As we read these words today, we may be confused by the diagnostic impressions drawn from the case. We may have a sense of regret that some of our current knowledge was not available to help this dying man, or we may feel secure that our contemporary medicine is superior to these earlier times. Perhaps reading this chart entry confers on us readers a sense of humility, knowing full well how primitive will our medicine appear in another century and a quarter.

In the way of all narratives, the medical record's form not only broadcasts but also influences meaning.[29] Our interpretation is influenced by the many temporal frames of life proposed by this very brief text. As we read of this death of the 24-year-old man in the context of the early deaths of both his parents, perhaps we notice the youth of death at that time and dwell on the relative age of death today. We hear in the grave diction of the writer —“very weak,” “very much weaker,” “gradually sank,” and “quietly died”—words of affect and affiliation. They are words that bespeak the presence of the doctor–writer as a witness as well as a technician and that rhetorically may elicit in the reader a corollary sense of witness. The contrast between the diction of 1884 and the less affective register of the language of today's charts alerts us to features of our own practice beyond its diagnostic or therapeutic processes. As the free space for narrative prose diminishes in our checklisted and templated electronic medical records, our waning ability to register the aspects of care that exceed the technical may preclude our very experiencing of them, perhaps impoverishing the care overall.

A contemporary account of a hospital death, like the excerpt below, displays a different sensibility and raises a fresh set of questions about hospitals, about deaths, and about the witnessing doctors. Although the genre and intention of the narrating differ from the St. Luke's Hospital chart—an oral dialogue intended to express the speaker's situation versus a written report intended to describe the subject's situation—this too is a singular account of a hospital death. Displaying this excerpt does not suggest that it is generalizeable to other deaths but proposes that such events can be perceived and represented in language, thus making them available for consideration and even contemplation. The following paragraph is an excerpt from a transcribed audio-taped interview with a third-year medical student who was asked by the interviewer, “Have you seen a patient die?” (R. Charon, MD, PhD, unpublished data, 2000).

> I saw one patient die. They had just announced a code overhead, and we ran, and my resident was doing chest compressions, and everything, and pushing the drugs, and all that, and then, at the end, they called—you know, the time of death, and it was over, and then everyone like, walked out of the room…[U]h, everyone walked

> out of the room, and the patient was just lying on the bed, naked. She had her head bent back, and the tube in her throat, and tape across her face, trying to hold it down, and her groin was all bloody from the multiple ABGs [arterial blood gas tests] we had done, or sent, and it just looked very horrible, and it was just very—everyone just left, like, they were like, okay, it's over now, and just left.

The speaker gives this story in a mixture of technical and colloquial dictions and a mosaic of genres, including the case presentation, the confession, and the accusation. The agency in the text is hard to locate—a "they" announces the code overhead, and then a different "they" calls the code. The patient, with no more agency than the teller, lies naked with her head bent back, and if anything, the tape, "trying to hold [the tube] down," has more agency than anyone does.

Ambiguity surrounds the "we" and the "everyone." The student seems to include himself or herself in the "we" who ran and who did ABGs. Yet, the student seems to exclude himself or herself from the "everyone" who left, the "everyone" who becomes a "they" while the speaker seems to have remained in the room with the corpse. Unlike the doctor–writer of 1884 who elicits an almost ghostly proximity in the doctor-reader, this student displays and might elicit from some readers an alienation from the collective "everyone" who, in fact, seems to become "everyone but me."

These two contrasting contemplations of deaths instruct us. They haunt us. The first seems to comprehend the inevitability of death, even as it comes to a 24-year-old man. The second treats death as a gruesome offense. The doctor's presence as witness in the first account shifts to the medical student's posture as intruder. It is as if the student has become the ghost. Studying both these clinical narratives exposes some of the otherwise hidden professional foundations of our clinical and pedagogical work in medicine, demonstrating the value of paying close attention to the stories we write of medicine and the ways in which we write them.

All involved in these episodes of giving and receiving of accounts of self are influenced by the stories. Narratology, the field of specialization in literary theory devoted to the structures and actions of narratives, reminds us to pay attention to the story (the events represented), the narrative (the written or oral text that results), and the narrating (the actual scene of telling).[30–32] By virtue of the *story* represented (the deaths as they occurred), the *narrative* crafted to represent them (the hospital chart note, the audio-taped paragraph), and the *narrating* that occurred to let it be told (the writing in the chart, the interview with the student, and now my reproduction of these stories for you to read), meaning accrues to these events. The tellings here collate many tales—this doctor in 1884 recounts the state of medical knowledge and interventional capacity at the time while signaling through his diction an affective presence. The medical student tells something important about the depersonalizing experience of medical training in the face of the hospital death. In being the recipient of these "narratings," each one of us undergoes something—perhaps to imagine the situations depicted, perhaps to remember similar events, perhaps to experience some connection or separation from the protagonists in the tales.

The Membranes of the Self

If giving and receiving accounts of self are the central events of health care, how, narratologically speaking, do they work? What happens when a sick person seeks health care? There may be a parallel to be found between the "membrane" between two persons talking—where their boundaries meet and even, in the physical exam, touch and sometimes invaginate in penetration—and the cellular membrane, of which we know so much. I think it is a generative metaphor. Doing what metaphors do, it does not point to a one-to-one

correspondence between two similar things but rather places in proximity two rather different things whose surprising contrasts suggest dimensions of both not previously appreciated.[33,34]

When two cells influence one another, one cell produces a ligand (that which links) that interacts with the second one's membrane to trigger it into action. When the ligand docks on the waiting membrane receptor, the inner portion of the receptor reaching deep into the interior of the cell undergoes change. An insulin protein docks on the insulin receptor of a hepatocyte, initiating phosphorylating enzymatic reactions at the inner portion of the receptor that ultimately turn on glycogen synthesis and lower the blood glucose. The ligand can be cleaved in the process of its reaction at the membrane receptor, and the response of the cell will vary, depending on the availability of substrate, the occupation of other receptors on the membrane, the up- or down-regulation of receptors themselves, or the presence of disease.

What are the ligands and receptors on the membrane of my patient and me, as we sit in my office? What is it that the patient secretes that activates my knowledge, memories, emotions, clinical judgment, and desire to be of help?

I think our ligands are stories. Stories and their receptors pierce the membrane of any reader or listener, including those who receive clinical stories. Activated from the outside—by reading, listening, witnessing, remembering—the receiver is altered by the story's docking while the story itself, like the docking insulin protein, can be altered by virtue of the contact. The story receptor's deep portion within the receiver triggers cascades of meaning-making in that reader's or listener's emotion, cognition, aesthetic sensibility, relatedness, capacity for attention, memory, and bliss.

We rely on having countless story “receptors” on our membranes ready to be activated by new experience. Having heard a story of death or alienation, I am better poised to activate my reception of a new one. This might be why the study of literature is helpful to doctors. There is currently a vigorous examination both among literary scholars and medical educators about the effects of reading on the reader. Does reading lead to empathy or to analytic distance? Are readers made “better people” by virtue of their reading experiences?[35–37] The membrane metaphor suggests a mechanism whereby reading might expand the meaning-making capacity of the physician faced with a sick person. As readers, we accrue banks of stories—Ivan Ilych, King Lear, Emma Bovary, Moses—that are then activated when some other story reminds us of them. As suggested by the long life of the feature “Medicine and the Arts” in this journal, it may be the availability within our memories of these many stories that enable the doctor to perceive something in a patient's account and then to wonder about it in productive ways.[38] Had the medical student and resident described in the transcribed interview above known some stories of death, the scene with the failed cardiac arrest might not have been so brutal. I wish they had read Virginia Woolf describing a death and its aftermath in *To the Lighthouse*. The following excerpt describes the house in which the Ramsay family lived and encountered several deaths—Mrs. Ramsay's daughter dies in childbirth, her son perishes in World War I, she herself dies during a night, and the house has been abandoned:[39]

> So with the lamps all put out, the moon sunk, and a thin rain drumming on the roof, a downpouring of immense darkness began. Nothing, it seemed, could survive the flood, the profusion of darkness which, creeping in at keyholes and crevices, stole round window blinds, came into bedrooms, swallowed up here a jug and basin, there a bowl of red and yellow dahlias, there the sharp edges and firm bulk of a chest of drawers. Not only was furniture confounded; there was scarcely anything left of body or mind by which one could say, “This is he” or “This is she.”

This paragraph proposes death's annihilation as both stark and universal, suggesting that its obliteration is understandable as a force of the natural. Death is described as a permeating darkness, as a confounding, as indeed should any death be experienced, when witnessed in the hospital or anywhere. Each reader of this paragraph and of the novel from which it is taken will make personal meaning, both aesthetic and ethical, of the text, which remains open for each reader's singular interpretation. And yet readers of this novel or even of this paragraph from it might by virtue of their collective reading come to know something about self and about one another in the shadow of this great text.[40]

If our ligands are stories, then what patients say can activate the clinician, causing cascades of transformative meaning-making reactions that culminate in contact, recognition, and clinical action. We clinicians need to populate our membranes with story receptors ready for docking by an individual story. Lest our receptors suffer down-regulation, they cannot be bombarded repeatedly by copies of identical stories but by always fresh ones. We need the internal equipment akin to the cell's enzymatic machinery ready to accomplish the interior transformations activated by the stories, including the powers of attention, representation, and affiliation, what we have called the three movements of narrative medicine. Those who train in narrative medicine develop the skills to attend closely to accounts of self given by others, to thereby enter others' alien narrative worlds, to provisionally accept these worlds as true and meaningful.[41] By representing what they hear or witness in words, they make visible to themselves what they have seen. They learn to peer around in other's narrative worlds to see where meaning might reside, to admit all possible light instead of just the most comfortable or convenient light. They become able to be quiet in the face of the words of another, to join with the other in affiliation, and to be moved by them to action. Evidence is accruing that narrative training can develop clinically and personally consequential capacities—including perspective-shifting, team cohesion, self-awareness, and reversal of burn-out—in clinicians at various levels of training.[42–47]

Narrative Medicine in Practice

I saw a patient in the office a few weeks ago. She had been diagnosed with breast cancer around twenty years ago, had a lumpectomy with five years of tamoxifen and was told she was cured. Recently, she developed a second cancer in the same breast. She treated this recurrence very matter-of-factly, submitting to a mastectomy, declining breast reconstruction, saying she was too old to need that. She recovered from the disfiguring surgery quickly, non-complainingly.

Then she began to worry that the cancer would come back again. She felt new lumps in the mastectomy scar and growths in the soft tissue under her arm. She was terrified that it would come back. She visited either the breast surgeon or me every other week. We did ultrasounds and tested her blood for cancer markers. We both kept telling her she was fine, that after an operation tissues shift as they heal, that her cancer markers were stable. She could not feel reassured, and so she felt we were deceiving her.

After another negative breast exam, I recognized what I thought might have felt deep to the scar for her, that is, a meaning hidden “below” the physical site of the operation. I thought she might be in the glare of the knowledge that she will die. I leaned back against the sink next to the examining table. I told her I could not reassure her that her body did not harbor the disease that would take her life. It might or might not be the breast cancer, but it will be something. I told her she had gained sight and courage from her last illness and that I thought she was now able to see what the rest of us hide from—that knowledge that we, too, will die. I offered to do something with her. I offered to stand with her as she gazed into that glare, to minimize its terrible isolation.

When I wrote the account of this office visit in my electronic medical record, I described what the patient had been going through. I described my assessment of the meaning of her fear of a third cancer, explaining that our role as her doctors was to stand with her in her fear. As I typically do, I gave the patient a copy of the note I wrote about her in her medical record.

I called the patient a few weeks after that visit to tell her I was thinking of her and that I had thought often about our conversation, a conversation that had moved me very much. She remembered our conversation very clearly. She said that since then, she had felt healthier, less afraid, sure that what we said together that day was right. She was very grateful for what we had done, and for my thinking of her in the interval. She continues to feel well now, months after that interaction.*

I came to understand what happened in this encounter only when I wrote it down, first in my chart note and then for this essay. The many narrative interventions in this case—my reformulation of the problem to wonder what was deep to the scar, my writing of it, my letting her read what I wrote in the chart, and my asking her to read this description for her consent to its publication—altered what I thought diagnostically and what she understood both of my thinking and of her clinical situation. Like any illness narrative, hers was not simply a report of a particular set of symptoms but rather an *exemplification* or a *showing forth* of how she lives, and, by extension, of what it might mean for any of us to live with illness.[48] These multiple narrative interventions economically brought us to a new level of trust, as we realized the reciprocal journey on which her situation had embarked us.

From my west-facing window in Greenwich Village, I have been watching Jupiter set in the night sky. By virtue of that view, I recognize myself as being a part of the cosmos—not just New York, not just Rita and her family, not just medicine, not just narrative theory and Henry James, but the total cosmos. Perhaps by virtue of the narrative work we do, we clinicians can expose the cosmic connections between medicine and all the other human enterprises that give and receive accounts of self, that enter through story-telling into contact, into relation, into world-making. Receiving our patients' stories mobilizes material deep within ourselves, transforms us, situates us at the threshold of illness with patients, humbly recognizing the patient and appreciating the magnitude of what must be done by that person, now at least not alone.

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*The patient read this description of her situation and signed informed consent, giving the author permission to submit this description for possible publication in *Academic Medicine*.

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